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ABSTRACT

This paper discusses the development of self-determination skills by students with disabilities and the role of the professional in promoting these skills. It begins by providing a list of 25 elements of self-determination and then explains the importance of promoting the development of self-advocacy groups and other endeavors initiated by and for individuals with disabilities. Basic leadership characteristics are provided, along with secondary leadership characteristics. Self-determination and leadership skills are compared, and barriers to leadership for individuals with developmental disabilities are identified. The paper discusses "truths" about leadership for people with disabilities, and provides a self-determination paradigm. Professionals are urged to provide people with disabilities with skills and information to express self-determination and the opportunity to obtain leadership positions, and to reform systems to provide greater opportunities for choice and self-direction. (CR)

Self-Determination, Self-Advocacy, and The Role of the Professional

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During recent years, there has been a strong emphasis on self-determination for individuals with mental retardation as a cluster of characteristics that lead to positive outcomes in adult life.

Individuals with developmental disabilities are expected to take control over the decisions made in their lives without any undue external influence or interference (Wehmeyer, Kelchner, & Richards, 1996.) The following table summarizes the most important self-determination characteristics that many authors emphasize when they try to define the self-determination concept.

Table 1.
25 Elements of self-determination

Sources: Field & Hoffman (1994); Powers, Singer et al. (1996); Sands & Wehmeyer (1996);
Wehmeyer (1998)

- | | |
|---|--|
| ♦ Knowledge of strengths and weaknesses | ♦ Internal locus of control |
| ♦ Self-realization, self-understanding and self-awareness | ♦ Setting, planning, and achieving goals |
| ♦ Assertiveness | ♦ Taking risks |
| ♦ Authority | ♦ Communicating and listening |
| ♦ Freedom | ♦ Negotiating |
| ♦ Support | ♦ Dealing with conflict and criticism |
| ♦ Responsibility | ♦ Evaluating outcomes |
| ♦ Determining what is important | ♦ Adjusting performance |
| ♦ Taking care of yourself | ♦ Problem solving |
| ♦ Decision-making | ♦ Self-regulation |
| ♦ Choice making | ♦ Leadership |
| ♦ Self-advocacy | ♦ Personal control |
| | ♦ Autonomous behavior |

Self-determination is a process as well as a result. Self-determination requires that the person possess various skills and competencies in order to achieve self-determined behavior. Most people, with disabilities and without, need to improve on some of the self-determination components listed above. That is why we believe that an important role of the professional is to support self-determination by establishing and making available materials and trainings related to self-determination.

Related to the self-determination philosophy, the leadership role of people with developmental disabilities is gaining popularity. As individuals with disabilities become more independent and have more control over their own life, there is an increasing need for leaders to promote the development of self-advocacy groups and other endeavors initiated by and for individuals with disabilities. Only self-determined persons can become leaders, but there are several characteristics that seem to be essential for successful leadership. Some important leadership traits are listed in Table 2.

Table 2.
Basic Leadership characteristics

Results of a survey on staff and clients published by John Johnson, *Leadership and Self-determination*, in *Focus on autism and developmental disabilities*, 14 (1), 1999, pp. 4-16)

- | | |
|--|--|
| <ul style="list-style-type: none"> ♦ Challenging the process ♦ Inspiring a shared vision ♦ Enabling others to act ♦ Modeling the way ♦ Encouraging the heart ♦ Collaboration ♦ Listening ♦ Rewarding other people ♦ Emphasizing small wins ♦ Energy/vitality ♦ Eagerness in accepting responsibilities ♦ Intelligence and judgment in action ♦ Task competence ♦ Understanding of followers' needs | <ul style="list-style-type: none"> ♦ Skill in dealing with people ♦ The need to achieve ♦ Capacity to motivate ♦ Courage, resolution and steadiness ♦ Capacity to win and hold trust ♦ Capacities to manage, decide, and set priorities ♦ Confidence, assertiveness, and command ♦ Ascendance, dominance, and assertiveness ♦ Adaptability and flexibility of approach ♦ Ability to differentiate illusion and reality |
|--|--|

Studies have shown that leadership is not different for people with disabilities, and that leaders have to possess the same basic characteristics to have the leadership status conferred to them.

Table 3.
Secondary Leadership Characteristics

- | | |
|--|--|
| <ul style="list-style-type: none"> ♦ Being a skilled speaker ♦ Having a keen interest in and understanding of people ♦ Possible interest in a professional career ♦ High energy and resourcefulness ♦ Willingness to confront individuals in authority ♦ High level of self-confidence ♦ High concern with moral issues ♦ Ability to develop relationships, interactions, and associations with a large number of people | <ul style="list-style-type: none"> ♦ Liking to expand sphere of activity beyond personal domain (e.g., traveling) ♦ Attuned to audience possibly posing questions, searching for guidance, looking for identity ♦ Developing a personal story and a position on it ♦ Having a story rooted in personal experience ♦ Developing affiliations with institutions and organizations ♦ Taking the opportunity for reflection to see the big picture |
|--|--|

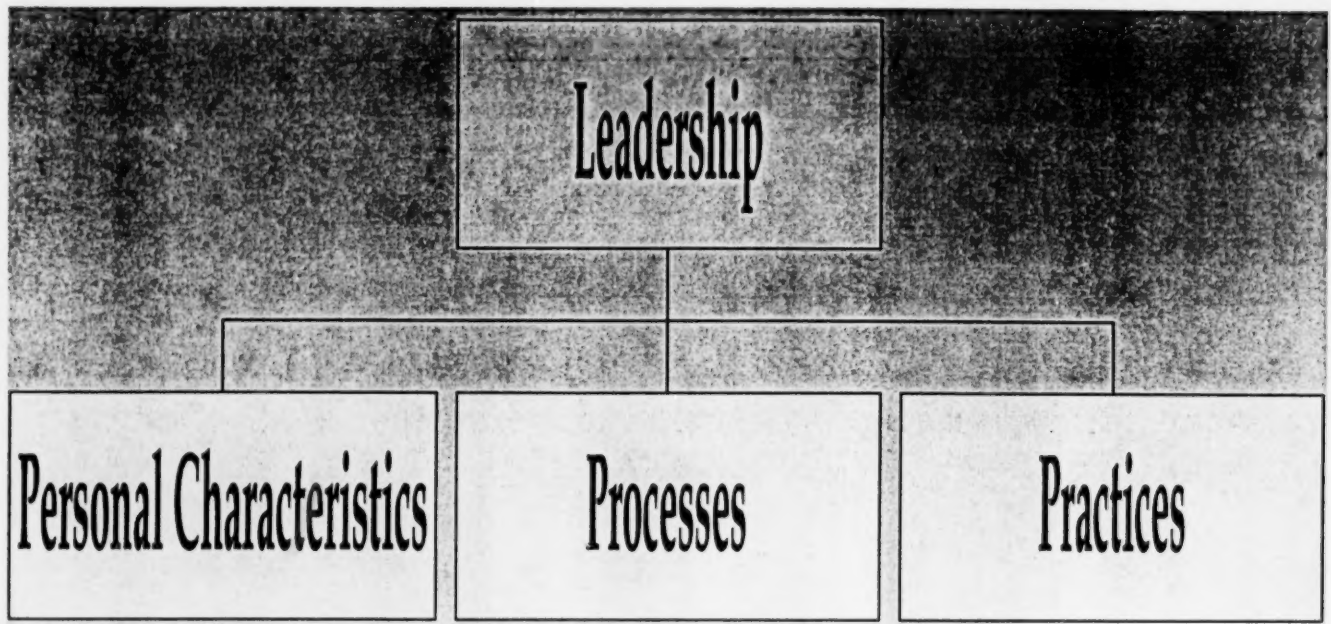
Comparison between Self-Determination and Leadership

Self-Determination	Leadership
♦ Focused on individual needs and concerns	♦ Focuses on collective needs and concerns
♦ Implies personal management skills and self-directed behavior	♦ Requires a "relationship" between leaders and followers
♦ Includes basic and inalienable human rights	♦ Leadership is conferred/acquired

Barriers to leadership for individuals with developmental disabilities

- ♦ Disability is regarded as antithetical to leadership
- ♦ Limited opportunities to lead
- ♦ Lack of peer education and support
- ♦ Leaders are isolated
- ♦ Lack of access to information
- ♦ Insufficient opportunities for leadership development

Structure of the Leadership Outcome



Truths about Leadership for people with disabilities:

- ◆ Leadership qualities are not different for people with disabilities as compared to general population
- ◆ The barriers to leadership for people with disabilities do not reside in their lack of abilities, but rather in their environment and opportunities.
- ◆ Leadership skills can be taught, but, for individuals with disabilities, as for everybody else, there is a "core" of qualities that must exist beforehand.
- ◆ Leadership might not be possible or even necessary for persons with more severe disabilities.

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The role of the professional

The professionals involved in self-determination activities typically focus on either one or both of these:

1. Providing people with disabilities with skills and information to express self-determination and have the opportunity to obtain leadership positions

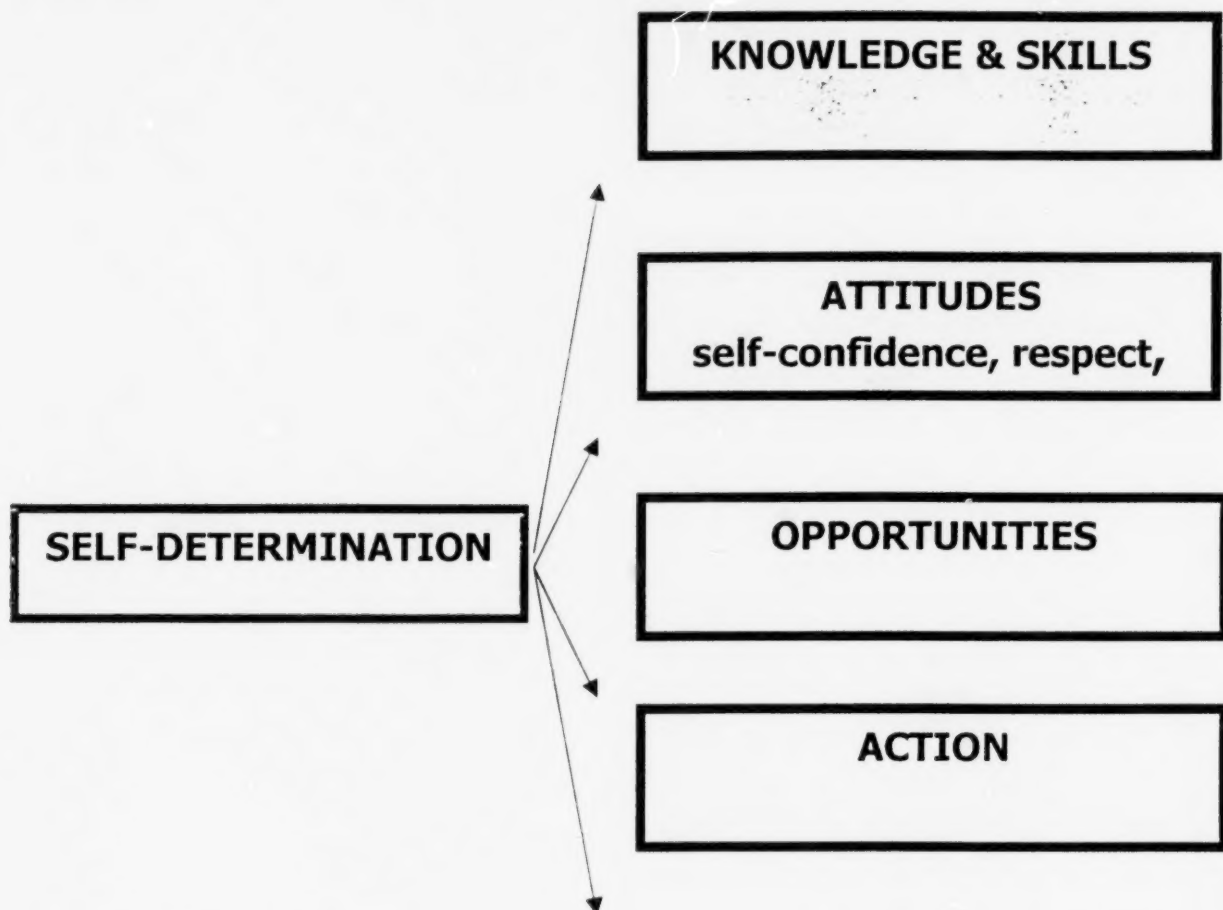
There have been increased efforts to develop programs that promote independence in people with developmental disabilities. Skills such as self-advocacy, self-actualization, psychological empowerment, decision-making, choice making, problem solving, and leadership skills have been the target of numerous training programs. Other efforts have targeted the generalization of the learned skills so that individuals with disabilities use self-determination skills in the community when it is needed. Using the mentioned skills makes it possible for them to be more easily included in the community, to secure and gain meaningful jobs, to make friends and keep them, to have satisfactory living arrangements, and, in general, to achieve more meaningful personal outcomes.

2. Reforming systems to provide greater opportunities for choice and self-direction

Another important direction is to work changing the present systems of education, care, vocational orientation, job training, and participation in different aspects of the social life. This change should be made together with the individuals with disabilities themselves and this is where professionals can offer support and guidance, as well as professional expertise.

In this difficult process of achieving self-determination, there are several challenges for self-advocates such as lack of experience, lack of support, society's fears – danger, liability, financial disasters, and the professionals should confront them together with the persons with disabilities. In order for the self-determination to happen, several things have to be in place: the person with disabilities has to possess the knowledge and the necessary skills, she or he has to have the right attitude, the right opportunities have to be offered, and, finally, the individual with disability has to take action (See the Self-Determination Paradigm on next page.) All these components hold essential roles for professionals from various fields.

The Self-Determination Paradigm



WHAT CAN OFFER THE PROFESSIONALS TO ENHANCE THE SELF-DETERMINATION PROCESS?

- Development of teaching programs for knowledge, attitudes, and skills required by the self-determined behavior. These programs should be designed for different ability levels.
- Technical assistance in the implementation of the teaching programs
- Staff training in current theory and best practices in the field
- Technical assistance for the creation and development of powerful and successful self-advocacy groups
- Designing and implementing strategies for the creation of adequate opportunities for self-determination in the environment of persons with disabilities
- Support the persons with disabilities to act upon their knowledge, skills, and attitudes towards the achievement of self-determined goals.
- Support with issues for individuals who exhibit dangerous or self-destructive behavior

Role of the Professional: New Challenges to be met!

- The role of professionals might differ in adult and children's services.
- Professionals in children services need to look at adult outcomes in order to design adequate services early enough in development.
- The liability of professionals might be affected by self-determination and there should be required safeguards to be determined.
- PROVIDING SUPPORT is probably the main professional role in a world of self-determination and it may mean support in acquiring skills, in decision-making or in working towards personal goals.